

## **PSYCHOLOGICAL FACTORS IN CHRONIC ODEMA: A CASE CONTROL STUDY**

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**Running title: Psychological factors in chronic oedema (CO): A case- control study**

**Abstract**

**Objective:** To examine psychological health and perceived social support in patients with chronic oedema (CO).

**Methods:** A random sample of patients who had been previously identified within a chronic oedema (CO) service in an urban area of south west London were group matched for age and gender with community controls in a case control study.

**Results:** One hundred and seven cases and 102 controls (women 82%) were identified. CO was caused by cancer or its treatment in 51 (48%) of cases and affected the leg in 65 (61%); the arm 41(38%) and the limb and midline in 15 (14%). Length of time with CO was long with 50 (47%) suffering for > 10 years. Cases were more likely to be single or divorced/separated ( $p=0.041$ ) and have reduced mobility ( $p < 0.001$ ).

SF36 scores showed cases had significantly poorer overall HRQOL in particular: physical functioning ( $p=0.003$ ); role physical ( $p<0.001$ ) general health ( $p=0.026$ ); vitality ( $p=0.015$ ); social function ( $p=0.007$ ) and role emotional ( $p=0.041$ ). EQ5D health index scores were significantly reduced in cases by 13 points ( $P= < 0.001$ , 95% CI 5.8, 21.6) compared with controls with a similar pattern for the VAS scale ( $p<0.001$ , 95% CI 7.6, 17.1).

The MOS scale showed cases had similar size social networks to the control group (5.8/6.6  $p=0.49$ ) but had lower total perceived social support scores (67.8/76.1  $p=0.018$ ). Cases had reduced support in all 5 domains with tangible and affectionate support significantly reduced for cases compared to controls.

Cases used significantly fewer coping strategies (COPE scale) than controls with regard to: active coping ( $p=0.024$ ); planning ( $p<0.001$ ) and use of instrumental support ( $p=0.006$ ). Significantly higher levels of coping were used by cases for the following domains: restraint ( $p=0.031$ ), positive reinterpretation and growth ( $p<0.001$ ); acceptance ( $<0.001$ ); denial ( $p<0.001$ ); mental disengagement ( $p<0.001$ );

behavioural disengagement ( $<0.001$ ): substance abuse ( $p=0.010$ ) and humour ( $p<0.001$ ).

**Conclusions:** Patients with CO have poorer health and greater impact on many aspects of HRQOL. While the size of social networks they report appear preserved, the levels of perceived social support are reduced. The pattern of use of coping strategies was complex with evidence of reduced problem solving combined with enhanced emotion focused coping such as acceptance and reinterpretation indicating illness adjustment. Deficits in the ability to function socially combined with perceived reduction in support and reduced mental health and emotional scores within the SF36 scale indicate the risk of developing psychological issues such as depression. Systems of care should offer an environment to address these issues.

## Introduction

### Chronic Oedema - an overview.

The term chronic oedema is now used interchangeably with the term Lymphoedema to describe swelling present for more than 3 months and arising from the accumulation of fluid and other tissue elements that would otherwise drain via the lymphatic system <sup>(1)</sup>. It can be a grossly disfiguring condition, usually affecting the limb, which causes discomfort, functional disability and symptoms such as pain. It can be complicated by recurrent infections often requiring hospital admission. Untreated, limbs can become huge, and the term elephantiasis illuminates their appearance. Recent research has shown that it affects many different patient populations and that people are found throughout the health systems <sup>(1)(2)</sup>. The cause of chronic oedema is often complex and includes: damage to lymphatics during cancer treatment, primary lymphoedema (due to problems in the development of the lymphatic system); damage to the venous system (phlebo-lymphoedema) and obesity <sup>(3),(4),(5),(6)</sup>. It occurs in those with chronic diseases affecting mobility such as spina bifida, multiple sclerosis and rheumatoid arthritis and in cardiovascular diseases <sup>(7)(8)(9)(2)</sup>. The prevalence is highest in the elderly with risks factors including obesity and reduced mobility, both of which are continuing to increase in western health care populations <sup>(1)(2)</sup>. Evidence from studies in cancer populations with CO indicates that the impact on health related quality of life is high <sup>(10)(11)12(13)(14)</sup>. Other psychosocial issues have received scant attention in patients with primary lymphoedema and within the heterogeneous patients affected with chronic oedema <sup>(15)</sup>.

The emphasis of treatment is on helping the patient to achieve as much self-sufficiency and independence as possible, given the chronic nature of their condition, and to reduce the incidence of co-morbidity and the need for intensive therapy and hospitalisation <sup>(16)</sup>. Treatment may involve an intensive phase (decongestive lymphatic therapy-DLT) that reduces the oedema. Methods include appropriate skin care, manual lymphatic drainage (MLD), multi-layer lymphoedema bandaging (MLLB), and isotonic exercise. The second phase of maintenance therapy may include self-bandaging, compression hosiery, exercise regimens, skin care and self-administered massage. Surgery and liposuction are used in selective cases but all require an element of patient self-management <sup>(17)</sup>. Drug therapy options are

currently of limited use except in selective cases <sup>(18)</sup>.

## **Psychosocial issues and Chronic Oedema**

There is increasing recognition of the role that psychological status plays in the development and outcomes of chronic disease, but little understanding of its importance in CO. Much of the quality of life research has been undertaken in patients following cancer, with a predominant focus on breast cancer related Lymphoedema <sup>(11)(19)(20)</sup>. This has highlighted the significant impact on emotional state, social isolation, reduced functional status and symptoms such as pain. Other issues such as the effects on body image and the ability to connect within the social environment and local culture have also been highlighted <sup>[21, 22]</sup>. All of these factors may affect long term psychological health.

Reliance on data drawn from specific patient groups fails to identify the impact in the wider range of patients. It is essential to understand the clinical, psychological and economic burden in order to negotiate for improved funding for this patient group in an increasingly challenged health care system. This study was designed to address this and by including a control group compare the additional burden of the disease.

## **Changing Psychosocial Burden**

Patients with CO often have complex co-morbidities with the potential to develop significant physical disability. As illness complexity increases, so may the psychological impact with the risk of problems such as depression, anxiety and social isolation. Treatment has followed a traditional medical model that focuses on reducing tissue oedema and stabilising skin changes, Very little attention has been placed on identifying and treating psychological problems or understanding the daily challenges faced by patients, families and carers <sup>(23)(24)(25)</sup>. There has been some attempt to de-medicalise management with the development of patient support groups <sup>(26)</sup>.

## **Coping, social support and health outcomes.**

The link between coping, social support and health outcomes is well established <sup>(27)(28)</sup>. Epidemiological studies for decades have shown that patients with cardiovascular disease show (though not always consistently) increased mortality in those who are socially isolated and decreased in those with good levels of support

<sup>(29)</sup>. There are a number of studies reporting an association between low social support and high levels of stress and negative health outcomes <sup>(30)(31)(32)</sup>.

Access to social support has been found to be significantly associated with positive rates of recovery in a range of conditions such as myocardial infarction <sup>(33)(34)(35)</sup>. Burn victims reported higher self-esteem and general satisfaction if they were receiving good social support <sup>(36)</sup>. A study of patients with hypertension found that social support was linked to better blood pressure control and maintenance <sup>(37)</sup>, and patients with kidney disease were found to have higher morale if they were within a supportive, cohesive family <sup>(38)</sup>. Finally, a study of 110 patients with chronic obstructive airways disease <sup>(39)</sup> identified that social support was linked to both the functional improvement of patients as well as survival.

### **Coping and Social support in Chronic Oedema**

There is a paucity of literature on coping and the social support needs of patients with CO, and much of what there is comes from the breast cancer literature. <sup>(40)(41)(42)</sup>. What is apparent, however, is that the psychosocial effects of such a chronic, outwardly disfiguring and restricting condition can be profound.

Studies have shown that women who develop the condition following breast cancer treatment exhibit higher levels of psychological, social, sexual and functional morbidity than women who do not <sup>(43)</sup>. Women who have poor social support, pain, CO in the dominant hand and/or a passive and avoidant coping style report the highest level of disability <sup>(43)</sup>. The literature points to the importance of widening our understanding of the psychosocial impact of CO by evaluating the place of coping and perceived social support.

### **Chronic oedema and health related quality of life**

Health related quality of life is a concept developed in an attempt to capture the impact of health and illness on a patient's physical and mental well-being as well as looking at the ability of the patient to function socially <sup>(44)</sup>. The emphasis is on the patient's own perception of their health and how illness impacts on all aspects of daily living and the relationship of the individual within their social environment. <sup>(45)</sup>.

The important point is that the severity of a condition is no longer defined solely according to clinical criteria. Assessment of health related quality of life, as a

subjective experience of the patient is a key consideration and will vary across age groups. For example the impact of the condition on employment, job prospects and relationships will perhaps be important to younger patients, while mobility and concurrent illness might have greater influence on how older patients perceive their quality of life.

In 2002 the King's Fund awarded a grant to develop and evaluate a model of care for patients with all forms of CO. The aim of this project was to develop, implement and evaluate health service and patient outcomes using an appropriate model of care within a London-based primary care trust (PCT). The work included undertaking a psycho-social case control study. The results are now reported.

The study set out to examine the following hypotheses:

- Patients with CO would have generally poorer psychosocial status, higher levels of disability and reduced health related quality of life compared to group matched controls drawn from representative general practitioner lists.
- Patients with CO would have small social networks and lower perceived social support
- Patients would use passive/avoidant coping styles and mental and behavioural disengagement strategies compared to controls

## **Study Aim**

To investigate the association between coping styles, levels of social support and health related quality of life in patients with CO compared to a community based control population.

## **Methods**

### *Study Design*

#### *Case identification and controls*

The general methods for the identification of patients in this study are provided in a separate publication <sup>(46 in press)</sup>. In summary, all patients with chronic oedema were identified through primary and secondary health services and offered treatment for their CO within a new service in south west London (UK). Following the case ascertainment 312 patients were identified and from this a random sample of patients were drawn stratified by age, gender and site of swelling. Cases were group

matched to control subjects drawn from six GP age sex registers within the catchment area. Group matching occurred for gender and age. Medical notes of all controls were screened at entry for CO and if a positive history was given they were excluded and replaced. Controls were contacted by a letter from their GP inviting them to attend the interview. Those who did not wish to take part, failed to attend the appointment or when screened were found to have CO at the interview were replaced by new controls. The format of the interviews was identical for both cases and controls and they were undertaken by the same researcher. The analysis was undertaken by group matching rather than on an individual basis. This allowed for the slight difference in the number of cases (107) and controls (102).

Patients were offered a choice of venue for the interview including their home or a health facility. The data collection tools included the following domains: (I). demographics , (II) clinical details, site of CO, complications and mobility status and (III) Psychosocial questionnaires (EQ-5D, SF36, MOS Social Support Survey, COPE scale ). Where standard questionnaires were included the instructions for completion were followed wherever possible. Patients and controls who could complete the questionnaires did so. Those who were unable to do so due to poor vision were assisted in the process.

The study was supported by a steering group of relevant experts including patients and carers. The data collection tools were piloted and amended with 5 patients prior to adaption and use. Ethical approval was obtained from the local Independent Ethics Committee (IEC) and the study was performed in accordance with the guidelines of the Declaration of Helsinki <sup>(47)</sup>, and the principles of Good Clinical Practice (GCP) ICH E6 and EN540 standards <sup>(48)</sup>.

#### *Patient Recruitment and Inclusion Criteria*

Patients were sequentially recruited to the study over a 15 month period following their identification and referral for treatment. The following inclusion and exclusion criteria were used:

##### **Inclusion**

- Patients with confirmed chronic oedema of > 3 months affecting the limbs and/or the trunk irrespective of the underlying cause
- Patients able to understand the study and give written informed consent

##### **Exclusion**



- Patients with advanced or terminal cancer
- Patients who were unable to speak English or complete the questionnaires
- Patients unable to give written informed consent.

### **Data collection tools**

A range of validated HRQoL and psychosocial tools were used in order to fulfil the objectives of the study.

#### **The MOS short form 36 (SF-36)**

The SF36 was chosen as a generic tool to assess health related quality of life because it has been used in other Lymphoedema populations <sup>(49)</sup> This is a well validated tool that provides estimates of eight health concepts, these being; physical functioning (PF), Role functioning-physical (PF), bodily pain (BP); general health (GH); vitality (VI), social functioning (SF), role functioning-emotional (RE) and mental health (MH). The responses to the 36 questions are transformed into the concepts to provide a scale from zero (worst possible health) to 100 (best possible health).

#### **The Euroqol (EQ5-D)**

The Euroqol (EQ5-D) was used to measure health status, the tool consists of five questions in the domains of mobility, self-care, usual activities, pain and anxiety <sup>(50)</sup>. The patients' health state is determined from the responses to these questions and fitted into an equation developed from a regression model. It produces scores from - 0.59 to 1.00, the lowest score being the worst possible health state and 1.00 being the best. Death is valued as zero within this scale. In addition, participants are asked to rate their health on a scale from zero to 100.

#### **The COPE scale**

The COPE scale was used to assess coping, <sup>(51)</sup>. It was chosen because it is a theoretically devised and validated scale that seeks to examine the multi-dimensional nature of coping and has been used in different chronic illness populations. The tool was designed to overcome the simplistic view that coping could be divided into problem focussed and emotion focussed coping. The tool has been validated as a situational (a real life event) as well as a dispositional tool (a generalised response to stressful events). This is particularly important in this study in which a control population was being examined.

The COPE scale consists of 13 separate domains including five subdivided as problem focused (active coping; planning; seeking instrumental support; suppression of competing activities and restraint coping) and five as emotion focused (positive reinterpretation and growth; acceptance; focus on venting emotion and denial). Further domains are (mental disengagement; behavioral disengagement; alcohol; seeking emotional support; humor and turning to religion).

The patients with CO completed a situational-based COPE scale where they were asked to consider how they coped with having the condition. The control population completed a dispositional version of the scale. This attempts to determine how people respond to difficult or stressful events in their lives.

The questionnaire was self administered in the study. Separate scores for each scale were calculated by adding the four scores from the items within each scale. The scores for each scale ranged from four to sixteen. The scores for each scale indicate the extent to which the type of coping is being used. Scores from the situational COPE were compared with the dispositional data from the control group to determine differences in the two populations.

### **The Medical Outcomes Study Social Support Survey (MOS)**

Despite the plethora of social support tools that have been developed, few have been shown to have robust psychometric properties. This situation is compounded by the lack of clear conceptual agreement over what constitutes social support <sup>(52)</sup>. The MOS has been developed in an attempt to overcome these issues. The tool is designed to represent the multiple dimensions of functional support: emotional/informational, tangible, affectionate, and positive social interaction.

The MOS is divided into two sections. The first section requires the patient to number how many close friends and relatives that they feel at ease with and can talk to about what is on their mind. This is defined as the social network measure. The second section involves 19 statements concerning different aspects of social support. Patients are required to make a response, nearest to their current experience, on a five-point Likert scale (None of the time - all the time). Each of the sub scales in the tool is scored individually. Scores are ordinally arranged with possible scores for the total 19 questions ranging from 19 to 95.

## **Data analysis**

Categorical data were analysed using logistic regression analysis with the dependent variable being the participants CO status (Case or control). Results were reported as both percentages of the total in each category together with odds ratios and 95% confidence intervals. The level of significance was derived from the logistic regression result.

Continuous data were analysed comparing the two groups (cases and controls). Results were presented as means (SD) together with mean difference and 95% confidence intervals. The level of statistical significance was derived from the t-test analysis.

## **Bias**

Attempts to reduce bias within the study were undertaken. This included drawing a representative sample from the wider group for age, gender and distribution of the site of swelling. Controls were drawn from the same geographical area and GP registers as for the cases. It is recognised that people with early chronic oedema will not be identified through this methods as they may not have yet presented to health professionals therefore the patients will be more severe than the total population affected.

## **Dealing with missing data**

Due to the frailty of some of the patients not all questionnaires were completed. This is reflected in the presentation of results in which the number of cases and controls completing the questions are identified within the tables. Health related quality of life results were adjusted for age and gender,

## **Results**

From the main case ascertainment through health services 312 patients who fulfilled the criteria for chronic oedema were identified. In order to reach the required sample of 107 cases, 120 people were required to be screened. The results for the cases and controls are presented in Fig 1. The main reason for non-selection for cases was failure to attend appointments or an unwillingness or inability to participate in the study. Cases were replaced according to the stratification until the sample was completely recruited. A similar procedure was used for controls in addition to screening for previous chronic oedema. The reasons for non-inclusion were similar to the cases. A total of 128 controls were screened to achieve the control sample.

Within the sample of cases (n=107), 88 (82%) were women. The mean (sd) age was 72.9 years in men and 68.6 years in women. Within the sample 77 (75%) were older than 70 years and 27 (25%) greater than 80 years. Only 27(25%) were under the age of 60. As expected given the age of the sample most people were retired (78%) with an additional 4.7% not working due to illness.

Chronic oedema affected the leg in nearly two thirds (65 (61%) with 41(38%) having arm swelling and a further 15(14%) having both midline swelling in addition to the limbs being affected. Cancer or its treatment was the cause of CO in 55 (52%) in whom 35(69%) had controlled cancer with only 1(2%) suffering metastatic disease. The swelling was of long duration with 50 (47%) suffering for more than 10 years and a further 54(51%) for between 1 and 10 years. Only 2(2%) had swelling for a short period (3 to 11 months). Cellulitis episodes occurred in 22 (21%) cases of whom 5 (5%) required hospital admission.

There were significant differences in the marital status of cases and controls ( $p=0.041$ ). More cases were single (19) or divorced or separated (18) compared to controls (11/8) ( $p=0.041$ ). No statistically significant difference was found in the living status between cases and controls although more cases were likely to live with a relative or companion (15/10) ( $p=0.64$ ). Cases had significant deficits in mobility with many confined to a chair or requiring a walking aid to achieve any level of mobility. The mobility status of the control group was significantly better (68/36)( $p<0.001$ ).

### **SF36**

Results from the SF36 reveal significant deficits in the HRQoL scores in cases compared with the control group (table II). In particular deficits were seen in physical functioning ( $p=0.003$ ), role physical ( $p<0.001$ ), general health ( $p=0.026$ ), vitality ( $p=0.015$ ), social function ( $p=0.007$ ) and role emotional ( $p=0.08$ ). However all other domains were reduced and approaching a standard level of significance.

### **EQ5D**

EQ5D health index scores were significantly reduced in cases by 13 points compared with controls (79/66  $p<0.001$ ). Results from the VAS scale show a similar difference 64/76 ( $<0.001$ ). The mobility questions confirmed the significant impact on mobility

with 68 (64%) of cases stating they had problems with walking or were confined to a wheelchair or bed compared to only 36(36%) of the controls ( $p<0.001$ ).

### **MOS Social Support Survey**

The number of people within the social networks of cases and controls were similar (5.8/6.6) ( $P=0.49$ ). The total scores for cases (67.8) were significantly lower than for the controls (76.1) suggesting an overall lower perceived social support ( $p=0.018$ ). Table IV shows that cases reported reduced social support for all the scales except for emotional/ informational support ( $p= 0.09$ ) and positive interaction ( $p=0.07$ ) both of which were approaching a standard level of statistical significance.

### **COPE scale**

Results from the COPE scale indicate that the patients used less problem and emotion focused coping strategies than the control group (table V). Cases used significantly fewer coping strategies than controls with regard to: active coping ( $p=0.024$ ); planning ( $p<0.001$ ) and use of instrumental support ( $p=0.006$ ). Significantly higher levels of coping were used by cases for the following domains: restraint ( $p=0.031$ ), positive reinterpretation and growth ( $p<0.001$ ); acceptance ( $<0.001$ ); denial ( $p<0.001$ ); mental disengagement ( $p<0.001$ ); behavioural disengagement ( $<0.001$ ); substance abuse ( $p= 0.010$ ) and humour ( $p<0.001$ ). Religious coping strategies were similar between groups ( $p=0.56$ ).

### **Discussion**

The results from this study would indicate that CO is associated with significant psychosocial morbidity. The demographic data from the cases confirmed that this was a predominantly elderly population who had been suffering with chronic oedema for a long period with less than half having CO as a consequence of cancer or its treatment. The proportion of women was high and there was evidence of significant impact on mobility. General health status was poor with a 13 point difference in EQ5D scores compared to controls. Elderly populations will experience a range of chronic diseases however the control group report an improved health profile suggesting that the patients with CO have a complex array of medical conditions resulting in swelling that is impacting on many aspects of life.

The study found substantial deficits in HRQoL and confirmed the first study hypothesis that patients with CO would have generally poorer psychosocial status, higher levels of disability and reduced health related quality of life compared to

GP/age/sex group matched controls drawn from representative general practitioner lists. The controls were drawn from the same geographical population at the same time. The differences observed therefore cannot be explained by temporal or regional differences between the two groups. Incorporation of a control group into this study has strengthened the understanding of the magnitude of the effect of CO compared with people of similar age and gender. Results from the EQ5D scores indicated the cases had significant health deficits. In a study to define utility scores in 277 patients with different causes of lymphoedema using the EQ5D scale the lowest scores occurred for those with lower limb CO secondary to cancer with the greatest in those with severe swelling and a high BMI. The EQ5D scores indicate a worse health status than in other published studies who report a mean score in the range of 80 compared to 66 in the current study <sup>(53)</sup>.

The second study hypothesis was that patients with CO would have small social networks and lower perceived social support. This has been partially supported with cases indicating low levels of social support however the size of the social networks were similar to the control group. Patients with poor psychosocial support available and low levels of information have been found to have high levels of anxiety and depression <sup>(54)</sup>. In this study cases had significantly lower levels of perceived support than the controls, suggesting that this may be an influencing factor. High levels of depression have consistently been associated with passive patient behaviour such as non- adherence to therapy <sup>(55)</sup>.

The results from the COPE questionnaire support the third study hypothesis that patients with CO would use more passive/avoidant coping styles and mental and behavioural disengagement strategies compared to controls. The overall pattern of results suggests that the patients with CO who completed a questionnaire based on their current experience, used fewer coping strategies than the control group who completed the dispositional version of the tool. It is not possible to determine how much the perceived differences can be explained by the use of a situational questionnaire in patients who are experiencing a real situation compared to those who are asked to make a judgement about how they generally cope with stressful situations. The control group may be over predicting the use of coping strategies that they believe they would use. In addition, the patients were all at different points in their illness experience. Evidence from the coping research has shown that patients with chronic illness tend to use more emotion focused strategies than problem

focused <sup>(56)</sup>. Patients may have undergone considerable adaptation which is influencing the pattern of coping strategies they use.

Little research has been undertaken to determine how patients cope with their CO with some evidence from the breast cancer population of a complex pattern of usage with men showing lower coping scores <sup>(57)</sup>. Those with melanoma and CO affecting the leg had worse quality of life and lower coping scales compared to those in whom the tumour was on the arm <sup>(58)</sup>. In a qualitative study of leg ulcer patients, Walshe described how patients used strategies which sought to normalise their condition in order to cope with the relentless demands of their condition and treatment <sup>(59)</sup>. Four main strategies were identified: coping by comparison, coping by feeling healthy, coping by altered expectation and coping by remaining positive.

The outcome of individual coping strategies on symptoms associated with CO is likely to be complex and to vary over time and be influenced by the disease trajectory. Suppression of activities that may increase the prominence of symptoms such as pain may be an important coping strategy that allows patients to live with their CO with less intrusion of symptoms and potentially with improved quality of life, however these may not be beneficial to overall control of oedema. Strategies such as exercise which may be viewed as important by professionals may be seen differently by patients who see no perceived benefit but do note that such activities increase their symptoms. This raises issues concerning how health beliefs influence the choice of coping strategy. It reinforces the issue that coping must be viewed flexibly and that the relevance of individual coping strategies may be influenced by many factors, not least the stage and severity of the patient's illness.

Patients appear to be using a similar pattern of coping to those found in other chronic illness populations, and strategies that may be considered more maladaptive such as use of alcohol, drugs and continuous periods of mental disengagement and denial were used in moderation <sup>(32)</sup>.

The results would suggest that the patients are socially isolated. It is not possible to determine whether the social isolation is a result of reduced social support or a consequence of the condition, which has been shown in other chronic illnesses. It could also be speculated that the patients are voluntarily withdrawing from social contact because they are aware of people's reaction to their condition. The debilitating long term effects of symptoms such as pain may also be influencing their

desire for social interaction. Problems of mobility are severe in this patient group and may influence their ability to socialise if they wished to.

The low levels of seeking instrumental and emotional support is evidenced despite the preservation of the size of their social networks. This indicates a more subtle effect on how people living with CO perceive support. The size of the social network may indicate they do not feel supported which is in turn reducing their overall quality of life status and increasing the perceptions of social isolation. Low levels of perceived support are likely to affect adherence to treatment and self efficacy and influence the effectiveness of the coping strategies that are adopted. These psychological factors in turn may influence clinical outcomes such as control of swelling and rates of complications such as cellulitis. For many these issues may trap them into a spiral of clinical and psychosocial deterioration.

The role of social support in control of CO has received little research attention. In patient populations with wounds, many of whom have concurrent CO, there is increasing evidence that social support may effect health outcomes. A number of studies in leg and foot ulceration report low levels of perceived support <sup>(60)</sup>. In addition there is some evidence of an increased rate of healing in those with high levels of support, while those with high levels of pain and depression had reduced healing even when adjusted for age and underlying aetiology <sup>(60)(61)</sup>.

Of the 107 patients a number were unable to complete the questionnaires due to a range of medical and psychological issues. It has long been recognised that these patients may be suffering from more extensive problems, but due to their condition they are unable to verbalise this. There remains a major research challenge to capture the impact of their suffering. This study was cross sectional in design, with patients being at different stages of their illness diathesis. Clearly the psychological status may vary over time, as will their social interactions. Tools such as the SF36 are generic and therefore they may not identify the more subtle quality of life issues associated with the specific condition. These tools also do not allow us to understand what the patients own expectations are about their condition, what would improve their sense of well being and which aspects of HRQoL they would like to see improved.

Current research has focused on the evaluation of HRQoL and attempts to determine changes with treatment. Clearly there is a need to understand in more depth the



aspirations of patients in order to ensure that they can function to their highest ability. This study would support that clinicians need to have greater awareness of psychological health problems in patients with CO and that services need to reflect the issues identified with access to psychological support to those showing distress.

### **Limitations of the study**

This study has a number of limitations. The sample size, although reflective of the larger population, is relatively small. The patients recruited are likely to be complex in their clinical presentation. However despite this fact there is evidence that they are typical of the types seen in current CO services in the UK <sup>(1)(2)</sup>. Many have had their condition for a long duration and have not had an appropriate diagnosis or treatment leading to deterioration and morbidity <sup>(1)</sup>. As there are no agreed coding systems or requirements to screen for CO in primary care it is likely that many with mild CO will not be identified and only become apparent when complications occur. Cases and controls were identified in the health care system and it is acknowledge that not everyone in the UK is registered with a GP and that transitory populations are not well represented in this type of research. The study used well validated generic HRQoL tools, however more recently disease specific tools have been developed that may be more sensitive to change and should be incorporated into future research <sup>(66)(67)</sup>. Despite this the tools adopted for the study have been able to identify significant differences between groups and importantly with other disease states.

### **Conclusion**

This study has highlighted the psychological impact that CO has on patients. There is a clear need to examine this in more detail particularly with respect to the differences experienced at varying stages of the illness trajectory and in the different manifestations of chronic oedema related to the array of associated medical conditions. The low levels of perceived support and increased levels of social isolation support the concept of services that allow for an integrated approach which includes psychological support and offers patient interaction, a relief from isolation and an opportunity to share common experiences.

## Tables

**Table 1: Comparison of Demographic and Social Factors.**  
*Values expressed as (OR) and 95% confidence intervals generated from logistic regression analysis.*

	<b>Controls N=102</b>		<b>Cases N=107</b>				
<b>Gender</b>	<b>No</b>	<b>%</b>	<b>No</b>	<b>%</b>	<b>OR</b>	<b>95% CI</b>	<b>p-value</b>
Men	19	19	19	17	1.00		
Women	83	81	88	82	1.06	0.52, 2.14	0.87
<b>Age</b>							
<60	27	26	27	25	1.00		
60-69	24	24	27	25	1.13	0.52, 2.42	
70-79	24	24	21	20	0.88	0.40, 1.93	0.88
80+	27	26	32	30	1.19	0.57, 2.48	
<b>Marital Status</b>							
Widowed	30	30	26	24	1.00		
Single	11	11	20	19	2.09	0.85, 5.18	0.041
Married	52	51	42	39	0.93	0.48, 1.81	
Divorced/separated	8	8	19	18	2.74	1.03, 7.29	
<b>Living status</b>							
Lives alone	37	36	42	39	1.00		
With spouse	51	50	45	42	0.78	0.43, 1.41	0.64
Relative/companion	10	10	15	14	1.32	0.53, 3.30	
Other	4	4	5	5	1.10	0.28, 4.41	
<b>Mobility status (Euroqol)</b>							
No problems walking	64	64	38	36	1.00		
Problems walking/ confined to bed	36	36	68	64	3.18	1.80, 5.62	<0.001

Table 2: Clinical details of the swelling		
	<b>Cases (107)</b>	
	<b>N (%)</b>	
<b>Site of swelling</b>		
Limb plus midline	15 (14%)	
Arm(s)	41 (38%)	
Leg (s)	65 (61%)	
<b>Cancer cause</b>		
No	55 (52%)	
Yes	51 (48%)	
<b>Cancer status</b>		
Controlled	35 (69%)	
Inactive	14 (27%)	
Metastatic	1 (2%)	
Not known	1 (2%)	
<b>Swelling duration</b>		
3-11 months	2 (2%)	
1-5 years	40 (38%)	
6-9 years	14 (13%)	
>10 years	50 (47%)	
<b>Infection over past year</b>		
None	85 (79%)	
One	14 (13%)	
Two	3 (3%)	
3-5	2 (2%)	
6-10	2 (2%)	
>10	1 (1%)	
<b>Admission for infection over past year</b>		
None	102 (96%)	
One	4 (4%)	
Two	1 (1%)	

Table III. Comparison of the SF-36 between cases with CO and controls								
	Control		Case					
	N	Mean (sd)	N	Mean (sd)	Difference	95%CI	t (df)	p-value
Physical functioning	102	67.6 (43.6)	107	48.9 (46.8)	18.7	6.4, 31.1	2.99 (207)	0.003
Role physical	101	71.2 (29.1)	107	45.9 (33.3)	25.3	16.7, 33.9	5.82 (206)	<0.001
Bodily pain	101	70.2 (29.9)	107	64.0 (30.9)	6.2	-2.1, 14.5	1.47 (206)	0.14

<b>General health</b>	101	67.1 (22.9)	107	59.5 (26.2)	7.7	1.0, 14.4	2.25 (206)	0.026
<b>Vitality</b>	101	59.4 (21.5)	107	51.5 (24.2)	7.8	1.5, 14.1	2.46 (206)	0.015
<b>Social functioning</b>	101	78.7 (31.5)	107	66.7 (32.5)	12.1	3.3, 20.8	2.71 (206)	0.007
<b>Role emotional</b>	102	78.4 (39.7)	107	66.4 (44.7)	12.1	0.5, 23.6	2.06 (207)	0.041
<b>Mental health</b>	101	78.1 (19.7)	107	73.3 (19.2)	4.8	-0.5, 10.1	1.78 (206)	0.077
<b>Euroqol</b>	99	79.3 (23.5)	103	65.6 (32.7)	13.7	5.8, 21.6	3.40 (200)	<0.001
<b>VA scale</b>	100	76.5 (15.5)	107	64.1 (18.9)	12.4	7.6, 17.1	5.14 (205)	<0.001

**Table 4. Differences in the mean MOS Social Support Survey scores (case-control).**

*Values given are the mean difference, (SEM) and 95% confidence intervals, t and p-value.*

	Control			Cases			Case – Control								
	N	Mean	SD	N	Mean	SD	Mean difference	SEM	95% Confidence interval			t-value	d.f.	p-value	
Emotional/ Informational	96	73.5	28.8	103	66.3	31.5	7.2	4.3	- 1.3	To	15.7	1.68	197	0.09	
Tangible Support	100	81.4	24.6	100	70.3	29.1	11.1	3.8	3.5	To	18.6	2.9	198	0.004	
Positive Interaction	98	73.6	28.8	105	65.6	32.4	8.0	4.3	- 0.5	To	16.5	1.85	201	0.07	
Affectionate Support	99	83.1	27.7	102	72.4	32.5	10.7	4.3	2.3	To	19.1	2.51	199	0.013	
Total Score	93	76.1	25.4	95	67.8	28.6	8.3	4.0	0.5	To	16.1	2.10	186	0.018	
Number of people	98	6.6	4.5	106	5.8	9.8	0.7	1.1	- 1.4	To	2.9	0.68	202	0.49	

Table 5. Differences in COPE scores (case-control).														
Values given are the mean difference, (SEM) and 95% confidence intervals, t and p-values.														
	Control			Cases			Case – Control							
	N	Mean	SD	N	Mean	SD	Mean difference	SEM	95% CI			t-value	d.f.	p-value
	Problem Focused													
Active Coping	100	10.8	2.7	103	9.8	3.2	1.0	0.4	0.1	To	1.8	2.28	201	0.024
Planning	100	10.3	3.0	102	8.7	3.5	1.6	0.5	0.7	To	2.5	3.58	200	<0.001
Use of Instrumental social Support	102	8.6	2.9	105	7.5	2.8	1.1	0.4	0.3	To	1.9	2.77	205	0.006
Suppression of Competing activities	101	6.5	3.2	102	6.9	3.0	-0.4	0.4	- 1.2	To	0.46	0.92	201	0.36
Restraint	101	7.0	3.3	100	7.9	2.9	-1.0	0.4	- 1.8	To	-0.1	2.18	199	0.031
Positive Reinterpretation And growth	102	8.9	3.6	102	10.7	3.5	-1.8	0.5	- 2.8	To	-0.8	3.66	202	<0.001
Acceptance	99	8.7	4.3	104	12.2	3.1	-3.5	0.5	- 4.4	To	-2.4	6.59	201	<0.001
Focus on Venting of Emotions	102	7.2	3.1	103	6.8	3.0	0.4	0.4	- 0.4	To	1.3	0.99	203	0.32
Denial	102	4.6	1.4	105	6.0	3.0	-1.4	0.3	- 2.1	To	-0.8	4.43	205	<0.001
Mental Disengagement	102	6.3	2.2	104	7.8	2.7	-1.4	0.3	- 2.1	To	-0.7	4.13	204	<0.001
Behavioural Disengagement	101	4.6	1.2	103	5.7	2.2	-1.1	0.2	- 1.6	To	-0.6	4.55	202	<0.001
Substance use	102	4.2	0.7	104	4.7	1.8	-0.5	0.2	- 0.9	To	-0.1	2.60	204	0.010
Use of Emotional social Support	101	6.6	3.4	105	7.1	2.9	-0.5	0.4	- 1.4	To	0.4	1.16	204	0.25
Humour	102	5.7	2.6	104	7.8	3.3	-2.0	0.4	- 2.8	To	-1.2	4.89	204	<0.001
Religious Coping	101	8.4	5.0	102	8.8	4.4	-0.4	0.7	- 1.7	To	0.9	0.58	201	0.56

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